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Acceptance of deafness: a study of family strategies and needs

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ACCEPTANCE OF DEAFNESS:

A STUDY OF FAMILY STRATEGIES AND NEEDS

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TABLE OF CONTENTS

Introduction . . . . . Page 1

Procedure and Sample . . . . . Page 2

Return . . . . . Page 4

Results. . . . . Page 5

Interpretations of Results . . . . . Page 15

Conclusions. . . . . Page 23

Reflections. . . . . Page 29

References . . . . . Page 30

Appendix

Cover letters

Questionnaire

After first learning of their child's hearing impairment, it is common for parents to experience strong emotional reactions. They may deny the hearing impairment or deny its permanance. Parents may experience feelings of sadness, disappointment, hurt, guilt, embarrassment, shame, blame, anger, and bewilderment. They may feel alone and isolated from the rest of the world.

Parents of hearing impaired children need to comprehend what it means to be deaf and then accept the concept of deafness within their child. When there is an honest understanding of the hearing loss and an acceptance of that loss, parents can more clearly provide for their child's needs and see their child's progress.

The process of acceptance is often slow and difficult, and some parents never fully accept their child's hearing impairment. In reading literature pertaining to this subject, I discovered that most professionals agree that parents benefit greatly from both individual and group conferencing or counseling. Such interactions between parents and a professional counselor, teacher, school administrator, or audiologist, play an important part in helping parents understand and accept their child's hearing impairment. Group conferences with professionals and other parents of hearing impaired children provide contact with others who are experiencing similar situations.

I was particularly interested in how the parents of children attending Central Institute for the Deaf (CID) view such conferences, counseling sessions, or meetings. I was also interested in determining whether mothers and fathers react differently to discovering their child is hearing impaired, and whether they utilize different strategies for accepting this handicap. In addition, I was interested in how siblings and grandparents of hearing impaired children deal with the acceptance process, and whether parents feel a need for conferences to help their other children and the grandparents.

PROCEDURE AND SAMPLE

To carry out this study, I devised a questionnaire consisting of thirty eight questions. This questionnaire was mailed to all fifty eight parents (thirty one mothers and twenty seven fathers) whose children were enrolled in the lower school of Central Institute for the Deaf. CID is a private residential and day school for hearing impaired children, located in St. Louis, Missouri. The children enrolled in lower school range in age from three to six years. Approximately 90% of their parents had been previously inrolled in a parent-infant education program.

Each questionnaire was accompanied by two cover letters, one written by myself explaining the purpose of the survey, and one written by Mrs. Jean Moog, principal of CID. (See Appendix) Each parent was asked to fill out a questionnaire independently, and in cases where the mother and father lived apart, questionnaires were mailed to their respective addresses. Also included with each questionnaire was a stamped envelope addressed to me in care of Central Institute. Parents were requested to complete and return the questionnaire in one week's time. Two weeks after the mailing, a thank you letter was sent home with each child in the lower school or was mailed to the parents of residential children. This letter also included a reminder for those parents who had not as yet returned the questionnaire.

One mother requested an interview, to be conducted at CID, to discuss the questionnaire. Following the interview, I was able to complete the questionnaire based on our conversation.

The parents surveyed represent a large geographic area, although most reside in or near the St. Louis area. In addition, the parents comprise a wide social spectrum in terms of economic status.

The questionnaire itself addressed five main areas of concern:

1. Reactions to the initial diagnosis of hearing loss and to the professionals involved.
2. Strategies parents utilized to accept their child's hearing impairment.
3. Views on the types of services desired by parents to help them accept the hearing impairment, with the focus being on conferencing services.
4. Reactions of grandparents and siblings to the hearing impairment.
5. Parental views on desired services for helping grandparents and siblings in the acceptance process, with the focus on conferencing services.

RETURN

Of the fifty eight questionnaires mailed, twenty seven were returned. This represents a 47% return. Of the twenty seven which were returned, seventeen or 63% were from mothers and ten or 37% were from fathers. Sixty percent (60%) of these questionnaires represented mothers and fathers who were presently married to each other.

The parents who returned questionnaires had a total of twenty hearing impaired children, (one parent has two children in the lower school), ranging in age from three to six years, with an average age of four years five months. Of the children represented in the sample 70% were male and 30% were female. Sixty three percent (63%) of the children live with both parents and 37% live with only one.

Three questionnaires were returned by hearing impaired parents while all of the others represent hearing parents of hearing impaired children.

RESULTS

A small number of the questionnaires returned, contained inappropriate answers or no answers to some questions. All of the statistics reproted represent only those answers which were complete and appropriate. In general, percentages were calculated for the responses. However, for some of the questions, the n was too small to calculate percentages meaningfully. In these cases, the results were reported numerically.

INITIAL SUSPICIONS AND DIAGNOSIS

The first section of the questionnaire concerned parents' suspicions and the subsequent diagnosis of their child's hearing impairment.

In 60% of the families represented in the survey, the mother was the first to suspect some type of problem. In 20% of the families, the father was the first. In the remaining 20% of the families, grandparents, friends, or professionals first suspected a problem. Eighty nine percent (89%) of those people who suspected a problem suspected a hearing loss specifically, while 11% did not know what the problem was.

Sixty eight percent (68%) of the children were taken to a pediatrician upon suspicion of a problem, yet only 5% of the pediatricians actually diagnosed a hearing loss. Most parents reported that the pediatrician found nothing wrong with the child, although a few physicians did recommend an audiologic exam. Of those children who were misdiagnosed by their pediatricain, 65% were correctly diagnosed by an audiologist, and 30% by and ENT. The average time lapse between the first suspicions of a hearing loss and the final diagnosis was five months. This does not include cases in which the hearing loss occurred subsequent to spinal memingitis.

Parents whose children were misdiagnosed by a pediatrician reported feeling dissatisfied, and most insisted on further testing or a second opinion. One father stated that while he was temporarily relieved, he still felt something was wrong.

Upon discovering that their child was hearing impaired, both mothers and fathers reported a wide variety of reactions. These included feeling worried, numb, angry, upset, disbelief, and even relief at finally discovering the hearing loss. No single emotional reaction stood out as being felt most often. Both mothers and fathers appear to be very individualistic in their reactions.

ACCEPTANCE STRATEGIES OF PARENTS

The next section of the questionnaire dealt with the strategies parents used to accept their child's hearing impairment, and the services they would have liked to have had available to assist them.

The parents were requested to rank order the strategies or resources they had used or were presently using to help them accept their child's hearing impairment. On the questionniare, six possible choices were listed, including a space in which parents could write in their own strategy or resource. Although the answers were extremely varied, a slight majority of the mothers reported that they were primarily just coping by themselves. ..ost of the mothers ranked help from their spouses, third or fourth, and help from their friends last. A substantial number of mothers reported that meeting other parents of hearing impaired children was the most helpful to them. Very few mothers ranked conferencing with professionals as being the most helpful, but most ranked this second or thrid.

The fathers' answers were also extremely varied. However, the majority reported "coping themselves" as being the most helpful and their wives as being the second most helpful. Again, friends were ranked last. The most common strategy, other than those listed, was help from the child's grandparents. Fathers generally ranked the grandparents third or fourth. Conferencing with professionals was the most varied response. It was ranked in every position and several fathers did not include it at all in their response.

Seventy six percent (76%) of the mothers and 60% of the fathers reported that they had had a meeting or conference with an educational or counseling professional in which they had discussed accepting and dealing with their child's hearing impairment. The majority of the parents attended this meeting for the actual purpose of discussing this topic. Most of the parents met in a school or in a parent-infant program, although two of the mothers met in a hospital and one mother and one father met in a clinic. Those parents who received conferencing services in a parent-infant program met in groups, although a substantial number met with professionals individually as well. Those who received services in a school, generally met with professionals on an individual basis.

Nearly all of the mothers felt that both the individual and group conferences were very helpful. They reported that the conferences answered their questions, provided them with hope, and eased their pain. Those who had attended group conferences felt that being around other parents of hearing impaired children helped immensely. One mother reported that she would have liked to have met with parents of older children and CID graduates in her group conferences. It is interesting to note that in the program in which parents were surveyed, some services which parents said they wanted actually were availbable, but parents may not have taken advantage of such services.

The fathers were equally as positive regarding individual and group conferences. They also felt that they were helped by being around others who shared their problem.

One hundred percent (100%) of the mothers felt the professionals they had dealt with were supportive. While the majority of fathers also felt this way, one reported that the professionals discouraged him from observing his child and "put on a show" when he did observe.

Another father felt that the professionals were not sympathetic and treated his child's hearing impairment as an everyday occurance.

In one question, the parents were asked to rank order those services they would like to have available if they had to re-experience discovering their child's hearing impairment. They were asked to choose only those that were not available to them previously.

The majority of mothers ranked group conferences with other parents of hearing impaired children as being their number one choice, even if this had been available to them. Individual conferences and an opportunity to talk with parents of older hearing impaired children were ranked second and third respectively. Mothers, almost unanimously, ranked reading literature on the subject of deafness and its implications last. It is of interest to note that three of the mothers reported that all of these services were available and used.

In contrast, the majority of fathers ranked individual conferences first, literature on the subject of deafness second, an opportunity to talk with parents of older hearing impaired children third, and group conferences last. One father's first choice was a conference with the child's physician.

Twenty three percent (23%) of the mothers who had attended a conference to discuss coping with their child's hearing impairment attended alsone. Thirty nine percent (39%) attended with their spouse, and 23% attended some confereces alone and some with their spouse. In addition, 15% attended with a friend or their mother.

Sixty seven percent (67%) of the fathers attended the conferences with their spouse, and 33% attended some of the conferences alone and others with their spouse.

Of those parents who would have liked to attend or would like to now attend a parent's group, 27% of the mothers reported that they would

prefer to attend alone, and 60% would prefer to attend with their spouse. Thirteen percent (13%) of the mothers would prefer both opportunities. One hundred percent (100%) of the fathers reported that they would prefer to attend with their spouse.

Among the parents who had never conferenced with a professional regarding their feelings and reactions to their child's hearing impairment, 22% of the mothers wished they had, 67% would like to in the future, and 11% do not want to have such a discussion. The father's responses were quite different. Twenty five percent (25%) wished they had conferenced, 25% would like to in the future, and 50% do not want to have a meeting with a professional.

Of all of the parents, both mothers and fathers, who had conferenced with an educational professional regarding acceptance of their child's hearing impairment, 100% responded that they would recommend this as being helpful to other parents who have a hearing impaired child.

GRANDPARENT REACTIONS AND COPING STRATEGIES

The next section of the questionnaire focused on the reactions of the hearing impaired child's grandparents, and the strtegies they utilized to accept the hearing loss. Parents were asked to comment on their own parents as well as their spouse's parents.

In general, most of the respondents did not feel that either their own parents or their spouses parents had had or were having difficulty accepting their grandchild's hearing impairment. (Table 1 describes the statistics.) Interestingly, 100% of the fathers responded that neither their parents nor their spouse's parents were having any difficulties in this area.

The mothers who felt the grandparents were having difficulty accepting the loss were extremely diverse in their responses about how this difficulty has manifested itself. Some felt that either their own or their spouse's parents were too lenient and felt sorry for the hearing

Table #1

	My Parents		Spouse's Parents	
	Had difficulty accepting hearing loss	Had no difficulty accepting hearing loss	Had difficulty accepting hearing loss	Had no difficulty accepting hearing loss
Mothers	25%	75%	25%	75%
Fathers	0%	100%	0%	100%

impaired child. Others felt that the grandparents ignored the child, became frustrated, didn't take the time to listen, or felt uncomfortable communicating with the child.

Both mothers and fathers responded to the question concerning how the grandparents were dealing with their acceptance even if they felt there was no problem. Most of the parents answered that the grandparents were talking to them to aid in the acceptance process. Five of the mothers responded that their own parents had visited CID to learn about the program. Other strategies included: doing nothing, ignoring the hearing impairment, talking to the child, and reading literature.

According to the mothers' responses, none of the grandparents had ever had a conference with an educational or counseling professional. However, one father answered that one of his child's grandparents had attended a group conference which was very helpful.

Fifty four percent (54%) of the mothers responded that they would like their own parents to attend a gradparents' or parents' group to help them deal with their grandchilds hearing impairment. Similarly, 54% of the mothers would also like this service for their spouse's parents. Sixty three percent (63%) of the fathers would like group conferences for their own parents, and 57% would like them for their spouse's parents.

Very few of the parents responded to the question dealing with how the grandparents' difficulty in accepting their grandchild's hearing impairment has affected them (the parents). Four of the mothers felt the grandparents' advice was inappropreate because of lack of information. Three believed that the grandparents disagree with their child-rearing techniques, and one felt that they do not offer enough emotional support. Only one father responded to this question, and he felt that the grandparents disagree with his child-rearing techniques.

SIBLING REACTIONS AND COPING STRATEGIES

The final section of the questionnaire concerned the reactions and coping strategies of the hearing impaired child's siblings. Fifty eight percent (58%) of the families represented in the survey have one or more children in addition to their hearing impaired child.

A large majority of the parents, 75% of the mothers and 80% of the fathers, responded that their other children were not having trouble accepting or coping with their brother's/sister's hearing impairment. Parents who felt that one or more of their children were having difficulty, felt that this had manifested itself in a variety of ways. One mother responded that her child's school work has suffered. Another felt her child needed more attention, and still another mother responded that her child becomes upset when she is playing and her hearing impaired sister is too far away to hear her. Only two of the fathers responded to this question. One felt that there has been a noticeable change in the sibling's behavior, and the other responded that the sibling of his hearing impaired child becomes emotionally upset more frequently than before.

The mothers have tried to deal with these situations in a variety of ways. These include: talking to the children and explaining about a hearing impairment, explaining how they could help their hearing impaired brother or sister, and telling the children that they must learn to be patient. One mother asked her husband to give attention to their other child. (The husband does not live with the family). The one father who responded to this question asked his wife for help in dealing with this situation.

The final question in this section asked the parents to rank order those services they would like to have available to help their other children accept and deal with having a hearing impaired sibling. The majority responded that they did not desire any services since their children were coping well. Only one mother and one father wanted their children

to have individual conferences with a professional. The most common first ranked answers were group meetings with other siblings of hearing impaired children and an opportunity for their children to spend a day at CID. Simply written literature on the subject of deafness was generally ranked last.

It is important to note that all of the siblings who were having difficulty accepting their brother's or sister's hearing impairment were the eldest children in their families and the hearing impaired child was the youngest. It appears that the older children may have difficulty since they are at least somewhat capable of understanding the implications of deafness on the child as well as the whole family. When the hearing impaired child was the oldest, his/her siblings were far too young to even understand the handicap, and therefore, would not have trouble accepting it as yet.

A CONCLUDING QUESTION: ADVICE FROM PARENTS TO PARENTS

To conclude the questionnaire, the parents were invited to offer advice or emotional support to parents who recently discovered that his/her infant was hearing impaired. The responses were extremely varied and individual, yet a few suggestions did appear frequently. Eight mothers and six fathers recommended talking to professionals or other parents of hearing impaired children, or joining a parents' group. Four of the mothers and one father suggested getting the child to CID as quickly as possible. Six of the fathers and one mother recommended obtaining and reading information on education, diagnosis, and/or financial support. Three mothers and two fathers suggested that keeping faith in God and prayer would help them come to terms with their child's hearing impairment. Some of the other advice included: treating the child as normal as possible; providing the child with a lot of love, understanding, and attention; be

patient; knowing that acceptance takes time; not blaming yourself; talking to deaf adults; and recognize the needs of your spouse, your other children and yourself.

SINGLE PARENTS

All of the previously described statistics indluded responses from two-parent families as well as from single-parent families. In general, there was very little difference in the responses of these two groups. However, a few of the answers from single parents deserve additional attention.

Of the seven questionnaires returned by single parents, five were from mothers who have legal custody and are the primary caregivers of their hearing impaired child. The other two were returned by fathers who do not live with their hearing impaired child.

One interesting difference between single and married mothers was that four of the five single mothers preferred to attend conferences alone, while the majority of married mothers preferred attending with their spouse. Comparitively, 100% of both married and single fathers preferred to attend with their spouse.

Another difference between married and single fathers concerned the services they would like to have available if they had to re-experience discovering their child's hearing impairment. While the majority of married fathers ranked individual conferences as their first choice, both unmarried fathers ranked reading literature on the subject of deafness first.

None of the other responses of single parents were significantly different from those of married parents. However, this could be due to the small sample returned by single parents

HEARING IMPAIRED PARENTS

Three questionnaires were returned by hearing impaired parents. Although their responses were included with most of the responses of hearing parents in the statistics, these parents' emotional reactions and coping strategies were very different from those of hearing parents, and therefore were not included in the statistics pertaining to these areas.

All three of the hearing impaired parents reported that they easily accepted their child's hearing loss. One parent even reported feeling relieved that her child was hearing impaired. These parents were all coping well on their own, had never felt the need to conference with a prefessional to help them cope, and they did not wish to meet with a professional in this regard in the future.

Two of the parents who were married to each other, responded that both sets of grandparents accepted their grandchild's hearing loss very easily and had no need for conferencing. The third hearing impaired parent responded that her own parents were having difficulty accepting their grandchildren's hearing losses (there are two hearing impaired children in this paricular family). This mother felt her parents had never accepted her deafness.

All three of these prents recommended that other parents of hearing impaired children talk to deaf adults to ease their worries and aid them through the acceptance process.

INTERPRETATIONS OF RESULTS

After studying the results of this survey, I was able to observe some generalizations, trends, and common reactions. In the following section, I have attempted to discuss these generalizations, add my own interpretations, and compare my results to similar studies reported in the existing literature. I have chosen to comment only on those statistics which I felt warranted additional explanation or interpretation. All of the interpretations are based on my own opinions derived from the results of this study and from my review of the related literature.

RETURN

While a 47% return on a questionnaire is generally considered adequate for obtaining accurate information on a given population, the 47% return in this study only represents twenty seven questionnaires. This is probably too small a number to adequately assess the views of all the parents who have children in the lower school department of CID. However, from reading the completed questionnaires I sensed that those parents who did complete and return questionnaires felt that these issues were important and they wanted to express their opinions. Therefore, this limited sample of the total population probably does represent the reactions and opinions of those parents who would be most likely to use and benefit from a conferencing program.

It did not surprise me that only ten fathers out of twenty seven returned questionnaires. Although sex roles are changing in today's society, a good many fathers continue to play a minor role in care giving and child management. It would appear that only those fathers who have been actively involved in raising and educating their hearing impaired child would take the time to complete and return the questionnaire. Therefore, this sample of fathers' responses may represent a somewhat skewed view of the fathers of children in the overall population of the lower school.

Since the majority of fathers did not return the survey, I can only assume that they may not have a major interest in conferencing services. However, I do believe that the results of the ten fathers who did respond should be considered seriously as a representation of those fathers who would utilize group and individual conferencing services.

INITIAL SUSPICIONS AND DIAGNOSIS

In general, the results of the questions dealing with suspicions and diagnosis of hearing loss, reveal that while most parents seek professional advice from their child's pediatrician, most pediatricians postpone a diagnosis of hearing impairment, suggesting that parents "wait and see." This finding is in agreement with several other studies reported in the literature, which claim that the majority of doctors fail to recognize a hearing impairment in young children. (Shah et al, 1977; Shah, Chandler, and Dale, 1978)

Fellendorf (1970) noted that there was an average delay of eight and one half months between the time deafness is suspected in young children, and the time when it is diagnosed. My study, however, reveals only a five month delay between suspicion and diagnosis. There could be several reasons for this difference: 1) Since Fellendorf's study is thirteen years old it is possible that today's physicians and other professionals are more aware and knowledgeable about hearing impairments. 2) The size of the sample in my study could be too small to provide an accurate portrayal of this issue. And, 3) There could be a geographic bias in my survey due to the fact that most of the respondants reside in or near the St. Louis area. St. Louis has several reputable and prestigious institutions specializing in hearing impairments, including: CID, Cardinal Glennon Hospital, St. Joseph's Institute, St. Louis Children's Hospital, and Barnes Hospital. It could be that professionals in this geographic area are more familiar with congenital deafness, than professionals in the general United States population.

The results indicating the dissatisfaction of all of the parents whose children were misdiagnosed by a pediatrician, agrees strongly with the findings of a study conducted by Williams and Darbyshire (1982). They reported that 80% of the parents in their survey felt that family physicians have a tendency to disagree with or dismiss parents' suspicions. Family doctors and pediatricians must develop a greater awareness of hearing loss as well as a willingness to regard the parent as an "expert" on the child's problem, despite often ill-defined complaints. Unfortunately, the low incidence of hearing loss in the general population may continue to have an affect on physicians' unwillingness to suspect a hearing loss.

ACCEPTANCE STRATEGIES OF PARENTS

It is difficult, from the results of this study, to make generalizations regarding coping strategies used by parents. However, a few interesting trends deserve additional comment.

According to Williams and Darbyshire (1982), the literature concludes that "the psychological effect of sympathetic and effective management at the time of diagnosis, and immediately thereafter, was crucial to parents' realistic acceptance of permanent hearing losses and their subsequent involvement in constructive training procedures with their children." While more than three-fourths of the parents in my study had utilized professional conferencing services, the majority of parents reported that their primary coping strategy was "coping by themselves." Since nearly all of the parents felt that both individual and group conferences were beneficial, I was surprised that conferencing services were not ranked first among coping strategies. There may be several explanations for this: 1) Perhaps intermittant conferences a few times a year are not as effective as a more structured ongoing conferencing

program. 2) Some parents may feel uneasy initiating a conversation concerning their acceptance of their child's hearing loss. They may therefore attempt to cope on their own. And, 3) Some parents who feel they have "coped on their own" may not have been able to do so as effectively if they had not availed themselves of some input from professionals.

Both mothers and fathers reported that their friends had been the least helpful in aiding them through the acceptance process. The majority of lay people know very little about hearing impairments. Because of their lack of knowledge, they may tend to pity parents of hearing impaired children, and this could eventually lead to strained friendships. It is often difficult for some people to feel comfortable around handicapped people, and while friends are usually well-meaning, they may at times do more harm than good. It should be noted that parents surveyed in this study had young hearing impaired children. It is interesting to speculate whether parents' friends are more of a help to them once children are older and the crisis of diagnosis and initial intervention has passed.

One mother, in ranking her coping strategies, commented that she would have liked to have met with parents of older hearing impaired children and CID graduates in group conferences. I have learned, from my interactions with professionals at CID, that, both of these options have been the focus of PTA meetings. I believe that in some cases, services are available to parents, yet they either cannot or do not avail themselves of them. While I realize that sometimes parents are truly unable to attend PTA meetings, it would seem that parents are at least informed of them.

When the parents were asked to rank order those services they would have liked to have available if they had to re-experience discovering

their child's hearing impairment, mothers and fathers provided very different responses. The mothers ranked group parent meetings or conferences first, while the fathers ranked them last. It would appear that while mothers find comfort in knowing that they are not alone in their situation, fathers may feel uneasy voicing their feelings in front of a group of strangers. Since the fathers ranked individual conferences first, it would seem that they do feel the need to express their feelings to someone, but perhaps they are intimidated by a group. This finding may be significant for programs attempting to meet the needs of parents.

In general, conferencing, whether group or individual, and talking to parents of older hearing impaired children, were the services most preferred by the majority of parents. This finding is in agreement with the results of the study by Williams and Darbyshire (1982). They reported, "All parents (in the study) believed that counseling at the time of diagnosis, and on an ongoing basis, was the kind of support that would have eased the transition from initial shock to accepting and dealing with the requirements of the handicap."

There were some parents in the survey who had never conferenced with a professional regarding coping and dealing with their child's hearing loss. The majority of mothers in this group reported that they would like to have such conferences in the future. Only one mother reportd that she did not wish this service. The fathers, however, responded quite differently to this question. One half of the fathers stated that they would not want to have a meeting with a professional, and only one father reported that he wished to have a conference in the future. It appears from these results that mothers feel a greater need for conferencing services than do fathers. Perhaps this is due to the fact that in most of these households, the mother is the primary caregiver. She may therefore be more aware of the effects and implications

of the hearing loss on the child. If the father spends relatively little time with the child, he may accept the hearing loss on misconceptions or false hopes. He would therefore not see a need for professional conferencing. Also, it may be that the fathers who want and feel a need for conferences, attend them, while mothers may be more hesitant and occasionally keep their thoughts and feelings to themselves, even if they would prefer professional conferencing.

GRANDPARENT REACTIONS AND COPING STRATEGIES

In general, most of the respondents did not feel that either their own parents or their spouse's parents had had or were having difficulty accepting their grandchild's hearing impairment. This finding is in agreement with a statement by Dr. Ray H. Barsch in his book The Parent of the Handicapped Child. Barsch writes, "The general feeling is that negatism of relatives represents a problem to only a small percentage of the parents of handicapped children."

While the results of the questionnaire indicated that only one grandparent had ever attended a conference with a professional, the coordinator of CID's lower school, reported that seven grandparents had visited their grandchildren at school, and three had sat in on a conference during the fall or winter of 1982-83. Perhaps my results on this question are inadequate due to the small return. It appears that a greater number of grandparents than reported have sought counseling services or in some way become directly involved in their grandchild's education.

It is interesting that while the majority of parents felt the grandparents were not having difficulty accepting the hearing loss, over half of the mothers and fathers reported that they would like their own parents and their spouse's parents to attend grandparent's groups

or parents' groups to help them deal with their grandchild's hearing impairment. Perhaps more parents than reported do feel that the grandparents are having difficulty coping with the hearing loss. Also, many parents may want the grandparents to be more informed about hearing impairments, and to learn how to best communicate with the child, even if they do accept the loss. It may also be true that grandparents are accepting of the child because of groundwork laid by the parents. If so, parents may wish for help with this effort.

SIBLING REACTIONS AND COPING STRATEGIES

The majority of parents in this study did not feel that their other children were having difficulty accepting their brother's/sister's hearing impairment. Similarly, the general impression of a study by Barsch (1968) found that brothers and sisters of the deaf seem to accept their hearing impaired sibling & present no significant continuing problem to their parents in this regard.

Overall, the majority of parents did not feel a need for any special services to help their other children cope with the hearing impairment. As described earlier, this response may be biased by the fact that the parents included in this survey had, for the most part, very young children ranging in age from infants to about third graders. Of those who did wish services, most responded that group meetings with other siblings of hearing impaired children and an opportunity to spend a day at CID would be the most beneficial. It appears that most parents feel that their other children need to know they are not alone in their family situation, and need to observe how their hearing impaired sibling is being helped at school. Once the other children see that their hearing impaired sibling can lead a somewhat normal life, they will probably have less difficulty accepting the loss.

SINGLE PARENTS

In general, there appears to be little difference between the reactions and strategies of single parents as compared to married parents.

The answers of single fathers stood out markedly from all other parents on the question concerning services parents would like to have available to help them accept the hearing loss. While most parents preferred some type of conferencing service, the single fathers preferred to read literature on the subject of deafness. Since the two single fathers do not have custody of their hearing impaired children, they may be minimally involved, yet interested, in their child's educational plans. These fathers also may not realize the full impact of a hearing impairment because they do not deal with it on a daily basis.

HEARING IMPAIRED PARENTS

The responses of hearing impaired parents seem to indicate that, to them, having a hearing impaired child is a positive experience if not preferable to having a hearing child. These parents seem to be able to immediately accept their child's hearing loss, since they have already accepted and adjusted to their own. Hearing impaired parents therefore, have little, if any, need for professional conferencing services regarding accepting the deafness.

It is interesting that one hearing impaired parent reported that her own parents never accepted <u>her</u> loss and therefore could not accept their grandchildren's losses. Perhaps if effective conferencing services had been available to these grandparents when their own hearing impaired child was born, they would have less difficulty accepting their grandchildren's losses. One would hope that better services for families of hearing impaired children will avoid such tragedies in the future.

CONCLUSIONS

In light of the information gained from this study, I was able to draw several conclusions and outline a number of recommendations based on those conclusions. I hope they will prove beneficial in expanding services for parents of children at CID or similar programs.

This study was designed to determine how parents react to having a hearing impaired child and then to determine what strategies and resources they use to help them accept that loss. It was also designed to assess parental views on desired services for helping grandparents and siblings in the acceptance process. The main focus of the survey was on conferencing services for families with hearing impaired children.

I found that most parents seek advice from their pediatrician when they suspect that their child might have a physical or developmental problem. However, pediatricians generally do not diagnose a hearing impairment, and this can lead to a substantial delay before a parent's suspicions are confirmed. Therefore, I recommend that parents who suspect their child might have a hearing loss, or whose child is not responding appropriately to sounds, should seek additional advice from an audiologist or ENT if their pedicatrician fails to identify a loss.

Perhaps one way to assure that parents are aware of hearing handicaps, is to develop such awareness through the media. Public service announcements in newspapers and on both radio and television would be beneficial. These announcements could inform parents about what responses to sound and what language skills develop at certain ages in infants. In addition, articles about hearing, deafness, and language development in parenting magazines and other publications can inform parents of these developmental milestones.

Doctors, too, need to be more informed and knowledgeable of hearing impairments. Medical schools must address this issue more thoroughly in order to prevent uninformed pediatricians from causing unnecessary

delays in diagnosis. Of course, I realize that the incidence of deafness in the general population is very low, and medical training programs may feel it unnecessary to discuss hearing impairments in great detail. Nonetheless, doctors, especially pediatricians, need to be informed about pre-lingual hearing impairments if hearing impaired children are to be provided with the best treatment and education.

It appears that pediatricians are becoming more aware of and knowledgeable about hearing impairments, and perhaps they will become more accurate in their diagnosis or referral for such diagnosis in the future.

As I anticipated, both mothers and fathers reacted strongly and in a variety of ways upon discovering their child's hearing impairment. While parents utilize a number of strategies and resources to help them accept the hearing loss, most desire and benefit greatly from individual conferences and/or group meetings.

Currently the parent-infant program at CID offers individual conferencing services to all parents whose child is enrolled in the program. These conferences involve helping parents to understand and accept their child's hearing loss, as well as helping them to learn to communicate with their child. Group meetings are held several times during the school year. These provide parents with information on behavior management, child development, educational options, acceptance of the hearing loss, and related issues. These groups follow a lecture/discussion format in which parents are free to ask questions and comment on the topic being discussed, as well as discuss the topic with each other.

Once the child enters the lower school at CID, and from then on, the parents meet individually with the child's teacher and department coordinator. This usually occurs twice a year and involves discussion of the child's educational progress and goals. Individual conferences for

other purposes are available to parents who desire such services, but are not required. The only group meeting currently available are PTA meeting held two to three times a year. These meetings cover a wide range of topics, that vary according to parent interest.

In light of the existing services, I feel that a more comprehensive and ongoing conferencing program should be established at CID and at similar educational institutions.

I recommend that, in the parent-infant program, mothers and/or fathers meet individually with professionals on a weekly or bi-weekly basis to discuss learning to deal with and accept their child's hearing impairment. These meetings could be in addition to meetings concerned with communication techniques and educational programs and progress. I feel that group meetings should be held once a month for mothers and fathers of hearing impaired children to meet informally and share their thoughts, feelings, and reactions. A professional educator or counselor should organize and direct this support group, but I feel the parents themselves should play a part in deciding the focus and content of the discussions. At times, it may be appropriate for the professional to initiate the discussion, especially at the first few meetings. It would also seem appropriate for the professional to occasionally present content information which parents would then react to and discuss. At other times, parents of older hearing impaired children or graduates of CID might attend these meetings to talk with parents and answer their questions. If the group prefers, separate mother's and fathers' groups could be established. Attendance at any of the conferences, group or individual, should not be mandatory, but I feel they should be organized in advance, on an ongoing basis so that the parents themselves do not have to schedule them. Parents are more likely to attend prearranged meetings than to arrange them themselves.

When the child enters the lower school at CID, the conferencing program should continue. A professional educator of the hearing impaired, who has had experience in counseling is probably the most qualified person to assume the role of conferencing with parents on an individual and group basis.

I feel that individual conferences for the purpose of helping parents accept their child's hearing loss, should not be held on a regular basis, but rather, should be arranged when a parent needs or requests such services. However, I recommend that parents be notified in writing and in person by department coordinators if possible, that conferencing services are available at any time.

I also recommend that parent support groups continue to meet once a month for all parents who have children in the lower school. They may follow a similar format to that of the parent-infant program, taking into consideration the parents' needs and the age of their child. If the parents decide as a group to meet less frequently or end their sessions completely, the professional can adjust the meetings accordingly.

There are some parents whose child enters the lower school without having gone through the parent-infant program. In these cases, the parents may have little knowledge of hearing impairments and/or may require additional assistance in their coping strategies. For these parents, individual conferences should be set up on a bi-weekly basis for the purpose of helping them through the acceptance process. These conferences may be similar to the individual conferences held in the parent-infant program.

Once a parent's child moves into the middle and upper school departments at CID, I feel that the parent support group should take on a new focus. Hopefully, most of the parents will have come to understand and accept

the permanance and implications of their child's hearing loss. Now however, parents may have new concerns. These may include: homework procedures, behavior management, relations with normal hearing peers, mainstreaming, dating, adolescence, sex education, and drug abuse to name a few. I recommend that group meetings be held several times throughout the school year to address these and related issues. In addition, I feel that the parents of older children should be invited to arrange individual conferences at any time.

Throughout the entire conferencing program, beginning in the parent-infant program, a variety of literature should be available to those parents who wish additional information on hearing impairments and related issues. If the professional does not have access to such material, she should direct parents to libraries or institutions that may have such literature.

Once this conferencing program is established and operating, changes should be made to accomodate parental needs and wishes. For example, if a group of parents of older hearing impaired children desire monthly meetings, this service can be arranged.

I realize that group meetings are very difficult to schedule so that all parents may attend. Daytime meetings prevent many working parents from attending while evening meetings may prevent those who live a long distance from school from attending. Even the best of efforts at scheduling will unfortunately be inconvenient for some parents.

The findings of this study also reveal that while most parents feel their <u>own</u> parents did not have difficulty accepting their grandchild's hearing impairment, they would like them to attend grandparents' groups. I feel that grandparents should be encouraged to visit CID by themselves or with their grandchild's parents. They should also be informed that

individual conferencing is available to them if they desire this service. Grandparents' groups should be established bi-monthly while the child is in the parent-infant program. These could be run informally in the same format as the parents' groups. The meetings should be directed towards explaining hearing impairments and their implications, and demonstrating how to best communicate with hearing impaired children, as well as towards helping the grandparents accept the hearing loss. The group may meet more frequently if desired. When the child enters the lower school, the grandparents' group should only be continued if the members request it. If there are not enough interested grandparents to form a group, it may be more feasible to invite them to the parents' groups. Again, the purpose of conferencing services for grandparents should focus on educating them about hearing impairments and helping them learn to cope with having a hearing impaired grandchild.

Finally, the survey revealed that most parents did not feel their other children had or were having difficulty accepting their brother's/sister's hearing impairment. Since only a few parents requested group conferences for their other children, I would recommend that older siblings, age six and up, be invited to visit their hearing impaired brother or sister at CID. After this visit, the department coordinator or counseling professional should discuss the visit with him or her, answering questions, or just chatting informally. If the sibling wishes to visit or talk with the professional again, arrangements could be made for this.

I hope that these suggestions and recommendations will be beneficial in providing teachers, supervisors, and counselors with information that they may use to establish a conferencing program, to help parents, grandparents, and siblings accept their loved one's hearing impairment.

REFLECTIONS

I feel that this project was very successful, despite the small return of the questionnaires. I believe that those parents who did complete the questionnaires were honest and open in their responses, and appreciative of the opportunity to express their feelings on this subject. While I would have liked to have interviewed the parents personally, I felt that they would be more willing to express their feelings anonymously in a questionnaire. Therefore, while I believe that the format of the questionnaire was effective in accomplishing my purpose, I probably would have received a larger return if it had been shorter and less time consuming to complete. I enjoyed reading the responses and appreciate the efforts of all those who took the extra time to write their own stories of how they came to accept their child's hearing impairment. I strongly believe that this project was a worthwhile endeavor, and I hope the results will benefit parents of hearing impaired children in the future.

I would like to leave all of those interested in and concerned with this project with one final thought. This simple "anonymous" verse may describe an attitude that provides a goal for which parents and families of hearing impaired children must strive.

God grant me
the serenity to accept the
things I cannot change,
the courage to change the
things I can, and
the wisdom to know the difference.

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APPENDIX

CENTRAL INSTITUTE FOR THE DEAF

818 SOUTH EUCLID
SAINT LOUIS, MISSOURI 63110

PARENT-INFANT LANGUAGE
TRAINING PROGRAM
ORAL SCHOOL FOR DEAF CHILDREN

PROFESSIONAL TRAINING
RESEARCH LABORATORIES
SPEECH AND HEARING CLINICS

January, 1983

Dear Parents,

We hope you will take the time to complete the enclosed questionnaire and help Mrs. Berkowitz in this research project.

The results of this study may help us to provide better services to the families of hearing impaired children which will also be of great benefit to the children themselves.

Sincerely yours,

Jean S. Moog

Jean S. Moog
Principal

JSM:rs
Enclosure

PHONE: (314) 652-3200

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SPEECH AND HEARING CLINICS

January, 1983

Dear Parents,

My name is Lynda Berkowitz. I am a second year graduate student majoring in education of the hearing impaired at Central Institute for the Deaf. As part of the requirements to complete my degree, I am doing research on a project concerning parents' reactions to their child's hearing impairment. I am interested in parents' reactions and also in parents' opinions about counseling services related to living and coping with a hearing impaired son or daughter.

I would appreciate your assistance in completing and returning the enclosed questionnaire. You do not need to put your name on the questionnaire. All of your responses will be kept completely confidential.

Since I am interested in the reactions of both fathers and mothers, I would like to request that each parent fill out the survey individually, if it is possible for two parents in a family to complete the questionnaire. If a question does not apply to your situation, please leave it blank. Also, feel free to elaborate on any of your answers, using the backs of the pages if necessary.

Please return the questionnaire(s) in the enclosed stamped envelope(s) by January 24th. If you have any questions, feel free to call me in the evening at 567-7661.

I want to thank you in advance for your time and assistance. Your help in this project is greatly appreciated.

Sincerely,

Lynda Berkowitz

Lynda Berkowitz

LB:rs
Enclosure

PHONE: (314) 652-3200

Throughout this questionnaire, the term conference is used to refer to any meeting you have had with either a professional counselor, school administrator, teacher, or audiologist in relation to your child's hearing impairment. More specifically, the term conference is used to refer to your interactions with the above educational or counseling professionals that may have helped you deal with problems in accepting and/or understanding your child's hearing impairment. These interactions may or may not be formal sessions, and might refer to school conferences or any discussions with the above mentioned professionals.

A group conference, refers to a meeting with professionals in a group consisting of other parents of hearing-impaired children. This is also referred to as a parents' group.

1. My hearing-impaired child lives with:_____both parents
   _____one parent
   _____brothers
   _____sisters
   _____other relatives
   _____friends

2. Age of hearing impaired child?_____

3. Sex of hearing impaired child?_____male _____female

4. Your relationship to child?
   _____mother
   _____father
   _____other guardian (please specify)_____

5. Does your child wear:
   _____one body aid _____two body aids
   _____one behind-the-ear aid _____two behind-the-ear aids

6. Does your child wear his hearing aid at all times, except when sleeping, bathing, or swimming?
   _____yes _____no
   If not, please specify when he/she does not wear the aid(s)._____
   _____

7. Who first suspected that your child might have a problem?
   _____self _____spouse _____other (please specify)_____
   How old was your child at this time?_____years _____months

8. What did the above person suspect was your child's problem?

_____hearing loss _____other (please specify)_____

_____mental retardation _____did not know

9. Was your child examined by a pediatrician when a problem was suspected?

_____yes _____no

10. If so, what was the pediatrician's initial diagnosis and/or recommendations?

_____

_____

11. If your pediatrician did <u>not</u> diagnose a hearing loss, how did you discover that your child is hearing-impaired?_____

_____

_____

12. If your child was misdiagnosed by a pediatrician, or if no diagnosis was made, what were your reactions at the time?_____

_____

_____

_____

13. What were your reactions after you discovered your child <u>was</u> hearing impaired?

_____worried _____angry _____relieved

_____numb _____upset _____did not believe it

_____other (please specify)_____

14. Who actually diagnosed your child's hearing impairment?

_____pediatrician _____ear, nose, and throat doctor

_____audiologist _____other (please specify)_____

15. How old was your child when he/she was accurately diagnosed?

_____years _____months

16. Since learning of your child's hearing impairment, what has helped or is helping you to accept and deal with it? (Please number the following in the order of which helped you the most, "1" being the most helpful.)

_____coping myself _____conferencing or interacting with

_____friends professionals

_____spouse _____other relatives (please specify)

_____other (please specify) _____

_____

17. Which of the following occur when someone that you do not know notices your child's hearing aid(s)? (Check all that apply.)

_____they stare or become embarrassed and awkward

_____they talk very loudly to my child

_____they stop talking to my child

_____they tell me how sorry they are for me

_____they say nothing and relate to my child as if he/she is normally hearing

_____they say and do nothing

_____other (please specify)_____

18. What do you wish would happen when someone you do not know notices your child's hearing aid(s)?_____

_____

_____

19. Have you ever had a meeting or conference with an educational or counseling professional, (other than your initial meeting with an audiologist), in which you discussed accepting and dealing with your child's hearing impairment?

_____yes _____no

Was this meeting:

_____for the purpose of discussing this topic

_____for a different purpose, but we discussed this topic

If yes, did you meet: _____in a group _____individually

In what setting? _____clinic _____hospital _____school

_____parent-infant program

20. How helpful were those conferences? (Did you get out of them what you wanted and/or needed? What did you feel was especially helpful and/or especially lacking in those conferences? Do you have any suggestions to make those conferences more helpful?) Please explain._____

_____

_____

_____

_____

_____

21. Do you feel the professionals you have dealt with are/were supportive of you?

_____yes _____no

If no, why not?_____

_____

_____

22. If you had to re-experience discovering that your child is hearing-impaired, which of the following would you like to have available to help you deal with and accept his/her hearing loss? (Please number in order of which you would want most, with "1" being your first choice. Please choose only those that weren't available previously.)

_____group conferences with other parents of hearing-impaired children

_____individual conferences with a professional counselor or teacher

_____an opportunity to talk with parents of older hearing-impaired children

_____literature on the subject of deafness and its implications

_____other (please specify)_____

23. If you have attended a meeting or conference in which you discussed coping and dealing with your child's hearing impairment, did you:

_____attend alone

_____with spouse

_____with others (please list)_____

24. If you would have liked to attend or would like to now attend a parents' group, would you prefer to:

_____attend alone (separate father and mother groups)

_____attend with your spouse

25. If you have never conferenced with a professional concerning your feelings and reactions to your child's hearing impairment, do you wish you had or do you wish to in the future?

_____I wish I had.

_____I would like to in the future.

_____I wouldn't want to have such a discussion with a professional.

26. If you have ever conferenced with an educational or counseling professional and discussed your feelings and/or reactions to your child's hearing-impairment, would you recommend this as being helpful to other parents who have a hearing-impaired child?

_____yes _____no

If no, why not?_____

_____

27. Is or are your parents or your spouse's parents having trouble accepting or coping with their grandchild's hearing impairment?

My parents		Spouse's parents	
_____yes	_____no	_____yes	_____no

28. If yes, how has this difficulty manifested itself? (Check all that apply.)

My parents	Spouse's parents	
_____	_____	They continually suggest that I take my child to other doctors and/or that I take him for various medical treatments.
_____	_____	They are too lenient and feel sorry for my hearing impaired child.
_____	_____	They ignore my hearing-impaired child when he/she is with them.
_____	_____	Other (please explain)_____

_____

29. How are the grandparents dealing with this difficulty? (Check all that apply.)

My parents	Spouse's parents	
_____	_____	talking to me
_____	_____	doing nothing
_____	_____	ignoring the hearing impairment
_____	_____	visiting C.I.D. to learn about the program
_____	_____	other (please explain)_____

_____

30. If any of the grandparents have had a conference with an educational or counseling professional, was it:

_____group _____individual

How helpful was it?_____

_____

_____

31. Would you like your parents or your spouse's parents to attend a grandparents' or parents' group to help them deal with their grandchild's hearing impairment?

My parents		Spouse's parents	
_____yes	_____no	_____yes	_____no

32. How has the grandparents' difficulty in accepting and/or understanding your child's hearing impairment affected you? (Check all that apply.)

_____They never offer to babysit or help out with my hearing impaired child so that I can have some time to myself or with my other children.

_____They do not offer me enough emotional support.

_____They disagree with or contradict my child rearing techniques concerning my hearing impaired child.

_____Their advice is inappropriate because of lack of information.

_____Other_____

33. Do you have other children? _____yes _____no
Please list their ages._____

_____

34. Did or do any of your other children have trouble accepting or coping with their brother's/sister's hearing impairment?
_____yes _____no

35. In what ways did/does this manifest itself? (Check all that apply.)
_____There has been a noticeable change in his/her behavior.
_____His/her school work has suffered.
_____He/She becomes emotionally upset more frequently than before.
_____He/She refuses to bring friends home.
_____Other (please explain)_____

36. How have you tried to deal with this situation?

_____

_____

_____

_____

37. Which of the following would you like to have available for your other children to help them accept and deal with having a hearing impaired sibling? (Please number in order of which you would want most, "1" being your first choice).
_____individual conferences with a professional.
_____group meetings with other siblings of hearing impaired children
_____simply written literature on the subject of deafness
_____nothing, I think they are coping well
_____other (please explain)_____

38. What advice or emotional support would you offer to a parent who recently discovered that his/her infant was hearing impaired?

_____

_____

_____

_____

_____

_____

Thank you for your time and assistance!